

The Evolution of Parents' Beliefs about Childhood Cancer During Diagnostic Communication: A Qualitative Study in Guatemala

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PURPOSE

- 90% of children with cancer live in low- and middle-income countries (LMICs), where fewer than 40% survive
- Fatalistic cancer beliefs may lead to delayed diagnosis and poor outcomes
- This study explored the evolution of Guatemalan parents' cancer beliefs during initial pediatric cancer communication, and the sociocultural and contextual factors that influence these beliefs**

METHODS

- Guatemala: small but diverse country with 24 principal ethnic groups
- Unidad Nacional Oncología Pediátrica: national pediatric cancer center:
 - >500 newly diagnosed patients/year
 - Overall survival: 67%

Qualitative: audiorecorded natural conversations and semi-structured interviews

20 parents of children newly diagnosed with cancer

Recording of initial psychoeducation (w/psychologist)

Recording of diagnostic conversation (w/oncologist)

Semi-structured interview

- Thematic content analysis using a priori and novel codes
- Two independent coders

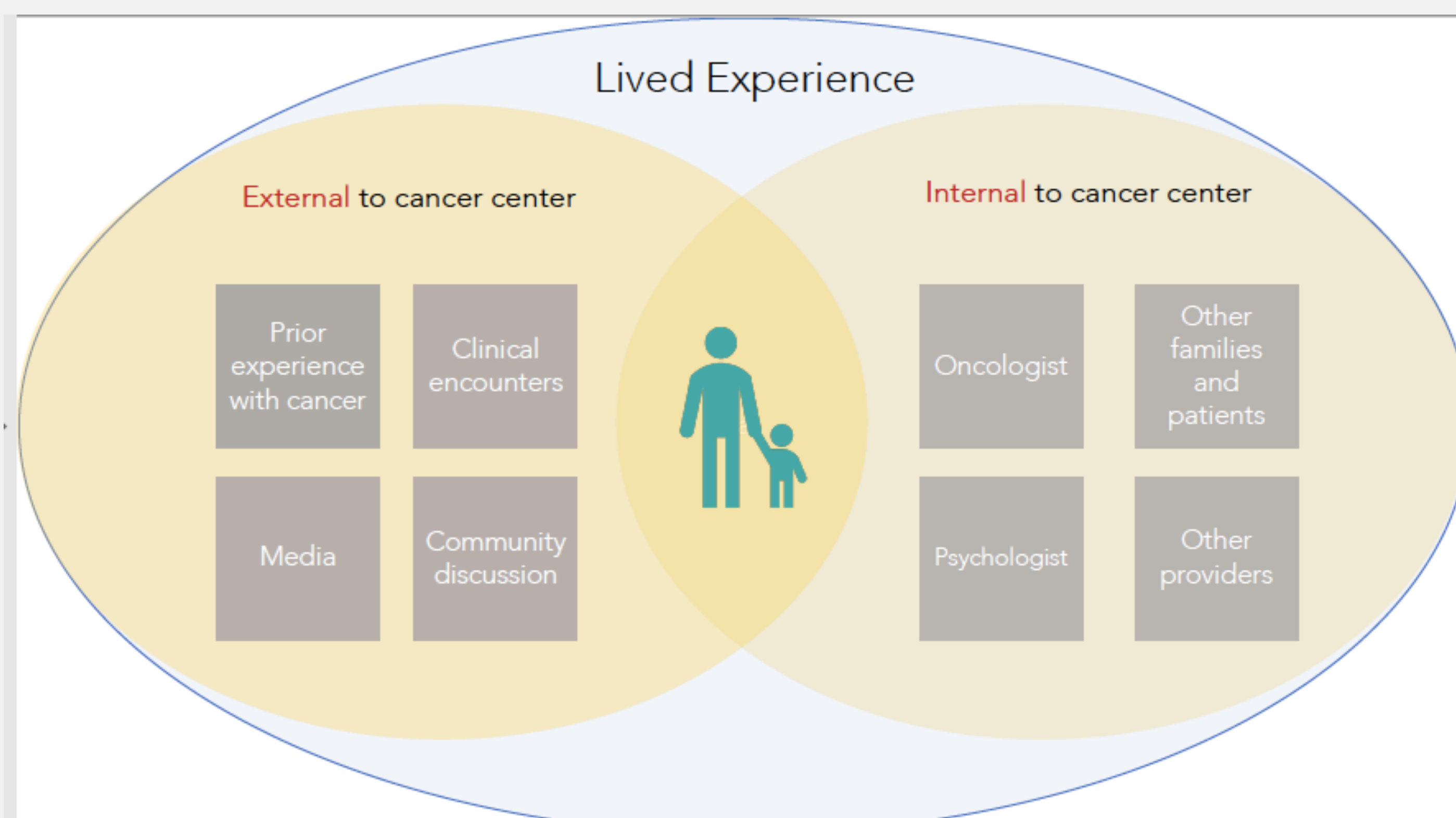
RESULTS

Demographics Numbers shown are n(%)

| | | | | | | | | |
|----------------------------|-------------------|---------|---------------------|--------------------------------|-----------|--|--------|---------|
| Patient Age | <4.9 years | 6 (30) | Mother's education | No school | 6 (30) | Parent present for psychosocial intake | | |
| | 5-9.9 years | 6 (30) | | Elementary education | 8 (40) | | Mother | 9 (45) |
| | 10-14.9 years | 4 (20) | | More than elementary education | 1 (5) | | Father | 5 (25) |
| | 15-18 years | 4 (20) | | Unknown | 5 (25) | | Both | 6 (30) |
| Patient Gender | Male | 11 (55) | Father's education | No school | 2 (10) | Parent present for diagnostic conversation with oncologist | | |
| | Female | 9 (45) | | Elementary education | 15 (75) | | Mother | 7 (35) |
| Diagnosis | ALL | 11 (55) | | More than elementary education | 3 (15) | | Father | 5 (25) |
| | AML | 2 (10) | | Mother's occupation | Housewife | | Both | 8 (40) |
| | Burkitt Lymphoma | 1 (5) | Father's occupation | Day worker | 1 (5) | Parent interviewed | Mother | 13 (65) |
| | Hodgkin Lymphoma | 1 (5) | | Professional | 1 (5) | | Father | 7 (35) |
| | Wilms Tumor | 2 (10) | | Unemployed | 1 (5) | | | |
| | Osteosarcoma | 1 (5) | | Dayworker | 1 (5) | | | |
| | Histiocytosis | 1 (5) | Number of siblings | Farmer | 9 (45) | | | |
| | High Grade Glioma | 1 (5) | | Professional | 8 (40) | | | |
| Religion | Evangelical | 13 (65) | | Unknown | 1 (5) | | | |
| | Catholic | 4 (20) | | None | 2 (10) | | | |
| | Other | 3 (15) | | 1-2 | 7 (35) | | | |
| Distance from the hospital | <2.5 hours | 4 (20) | | 3-4 | 6 (30) | | | |
| | 2.5-5 hours | 3 (15) | | >4 | 5 (25) | | | |
| | >5 hours | 6 (30) | | | | | | |
| | unknown | 7 (35) | | | | | | |

Sources of information contributing to parents' understanding of cancer

Guatemalan parents of children with cancer learn about their child's diagnosis through a variety of sources. Some of these sources of information are external to the cancer center, including prior experiences with cancer, media exposure, community discussion, and clinical encounters prior to reaching UNOP. Other sources of information are internal to the cancer center and include the psychologist, oncologist, other providers, and other patients and their families. A family's lived experience is a unique source of information that is simultaneously a culmination of all other sources and contributes to the family's ultimate understanding of cancer.



RESULTS

Pre-existing beliefs:

"We got worried because in the news I've heard that once you have cancer you don't have a good future."

"She was very down, so people started saying it was evil eye and 'susto', so we took her to the healer...they take some plants and rub her with them to cure the 'susto' and the evil eye."

Insights from parents on what they learned from the cancer center

| | |
|--|---|
| After encounters with the psychologist | "I understood, they explained it to me with seeds, like when a farmer sows; it's born, reproduces and dies." |
| | "Then when I came here, I changed my mind; I saw the place, the children, the psychologist talked to her, they explained it to her, and it was like a light of hope for a mom." |
| | "I also liked the way the psychologist talked to me, how she prepared me for the news, how she explained everything to me. She helped me a lot." |
| After encounters with the oncologist | "I thought there was no medicine, but the doctor told me that there is medicine." |
| | "My vision changed because it was told to me by a doctor, a person with experience, he gave me more hope." |
| | "I feel comfortable; sometimes we forget to ask some things, but the doctor always explains to me." |

- Psychologists acknowledge pre-existing beliefs and deliver cancer education
- Oncologist provide diagnostic information and treatment plans
- Both support hope

Lived experience:

"Yes, we heard about it, we heard about tumors, but hearing is different than saying face to face, this is what your child has."

Ultimate understanding:

"She said cancer is a bunch of bad cells, but chemo will destroy the cells."

"I thought there was no medicine, but the doctor told me there is medicine...if there is a solution for the disease, we thank God...I feel he is better with the medicine."



CONCLUSIONS

An interdisciplinary communication process that is attentive to pre-existing beliefs and supports hope may encourage acceptance of the allopathic medical model and need for treatment.

Providers in settings of all resource levels may be able to use similar techniques to support cross-cultural cancer communication, reduce treatment abandonment, and improve therapy adherence.

CONTACT

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